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How Helpful is Voluntary Stopping of Eating and Drinking (VSED) to Avoid Dementia?

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I. INTRODUCTION

My mother died at age 99, after more than 10 years of dementia, almost certainly Alzheimer's Disease (AD). She was a fiercely independent person all her life, and spoke often about her wish to commit suicide should she become unable to live independently. During her years with AD, she became increasingly dependent, unable to live alone or to care for her most basic needs. She became unable to speak, to recognize friends and family, or to enjoy any of her interests. So how did she end the way she did, and could voluntarily stopping eating and drinking (VSED) have helped her to end her life more in accordance with her wishes?

VSED is a strategy for conscious and capacitated persons to hasten their death by refusing all nutrition and fluids, whether by mouth or by other means (such as a feeding tube).¹ Most people who embark on VSED die within one or two weeks.² Hospice nurses describe VSED as a relatively comfortable way to die.³ Unlike physician-assisted suicide, VSED is legal in all US jurisdictions.⁴

In this paper, I look specifically at claims of VSED's efficacy in hastening the death of people with dementia. I argue that VSED is a weak tool at best. Given that 13.8 million Americans are expected to have

¹ Thaddeus M. Pope & Amanda West, *Legal Briefing: Voluntarily Stopping Eating and Drinking*, 25 J. CLINICAL ETHICS 68, 68 (2014).

² *Id.* at 69.

³ See Linda Ganzini et al., *Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death*, 349 NEW ENG. J. MED. 359 (2003).

⁴ Pope & West, *supra* note 1, at 69.

Alzheimer's Disease by 2050,⁵ and that Alzheimer's is surpassing cancer as America's most feared disease,⁶ dementia is an important context for evaluating the importance of VSED as a life-ending strategy.

This article is organized in parallel with the stages of Alzheimer's Disease as described by the Alzheimer's Association: early, middle, and late. I argue that VSED is not a useful strategy in any of these stages. We shall see that people in the beginning stages of dementia are unlikely candidates for successful VSED, while waiting until the final stages of dementia defeats the reasons why most people would want to hasten their deaths rather than experience long-term dementia.

II. THE LONG ARC OF ALZHEIMER'S DISEASE

Late Onset Alzheimer's Disease (LOAD) begins a decade or more before symptoms arise.⁷ Once the disease is diagnosed, the average span of time between diagnosis and death is eight years. The Alzheimer's Association describes the three stages as follows:

Early/Mild: The person may still function independently, e.g., drive, work, and participate in normal social activities. However, friends, family, or neighbors may begin to notice difficulties in remembering names or planning tasks; the person may begin to lose valuable objects. A physician

⁵ 2017 *Alzheimer's Disease Facts and Figures*, ALZHEIMER'S ASS'N., <http://www.alz.org/facts/overview.asp#quickFacts> (last visited Mar. 28, 2017).

⁶ *Americans Rank Alzheimer's as Most Feared Disease*, HELP FOR ALZHEIMER'S FAMILIES (Nov. 13, 2012), http://www.helpforalzheimersfamilies.com/alzheimers-dementia-care-services/alzheimers_feared_disease/.

⁷ *About Alzheimer's Disease: Causes*, NAT'L INST. AGING, <https://www.nia.nih.gov/alzheimers/topics/causes> (last visited Mar. 28, 2017). Late Onset Alzheimer's Disease (LOAD) accounts for more than 95 percent of Alzheimer's Disease. *Id.* A minority of people with Alzheimer's have the early onset, familial version, which stems from a dominant genetic mutation. *Id.* While there is some familial connection in LOAD, there are many genetic and environmental factors for LOAD, not all of which are known. *Id.*

attuned to the issue may be able to detect difficulties in memory or concentration.⁸

Middle/Moderate: This stage usually lasts the longest, with the person needing more and more care as the disease progresses.⁹ This stage is characterized by moodiness, increased memory loss, uncharacteristic behaviors, possibly incontinence, lack of attention to personal hygiene, and so on.¹⁰ The person may forget salient facts about herself (e.g., where she lives, if she is married), and fail to recognize family members.¹¹

Final/Severe: Persons can no longer respond to their environment, carry on a conversation or, eventually, control their movements.¹² They may lose the ability to walk, sit unassisted, or even to swallow.¹³ At this point, the person will need round-the-clock care.¹⁴

The above stages all exhibit clinically significant changes. However, there is general consensus among researchers and clinicians that the disease begins even before diagnosable symptoms exist. In this way of thinking about the disease, you could be diagnosed with LOAD even though you feel and appear to be perfectly well and unimpaired.¹⁵ The Food and Drug Administration has endorsed a “preclinical” or “prodromal” stage of LOAD, in which the disease is detectable only by various biomarkers (e.g.

⁸ *Stages of Alzheimer's*, ALZHEIMER'S ASS'N., http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp (last visited Mar. 28, 2017).

⁹ *Id.*

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ *Id.*

¹⁵ Jason Karlawish, *What We Talk About When We Talk About Alzheimer's Disease*, ROBERT WOOD JOHNSON FOUND. (Mar.12, 2012, 1:00 PM), <http://www.rwjf.org/en/culture-of-health/2012/03/what-we-talk-about-when-we-talk-about-alzheimers-disease.html>.

positron emission tomography (PET) scans for amyloid build-up) or perhaps very sensitive clinical testing.¹⁶

A. Early Stage LOAD

Although a person in the earliest stage of AD may seem the perfect candidate to employ VSED because she is still competent, in fact the characteristics of even this mild stage work against its success. When one is at the beginning of the long tunnel of dementia, self-awareness and executive function (the ability to form a plan and act on it) are among the first things to go. Here are two vignettes from the beginning years of my mother's life with early dementia, when she was still living independently, driving, and legally capacitated:

My mother returns from an outing with another elderly woman. "I feel so sorry for Ethel! She doesn't know what's what. She keeps asking the same question over and over again—it's very tedious." My mother exhibits no awareness that she herself asks the same questions over and over again. I cannot bring myself to tell her, and even if I did, she would probably not accept it.

Shortly after my father's death, my mother decides to get a cat. She mentions this to me and my brother; in fact she mentions it every time in our almost daily phone conversations. "Great idea, Mom! You should definitely get a cat. You know where the animal shelter is. Get a friend to go with you." Next day, next week, next month: "I'm going to get a cat." After a couple of months of this, I told my son, the next time he visited his grandmother, to take the initiative to go with her to get a cat. They did, and brought back Raven, who was a great success. My mother had a reasonable, consistent wish to do an easy and appropriate thing, well within her capacities, but there was a disconnect between her intention and

¹⁶ Ctr. for Drug Evaluation & Res., *Alzheimer's Disease: Developing Drugs for the Treatment of Early Stage Disease*, U.S. DEP'T HEALTH & HUM. SERV. (Feb. 2013), <https://www.fda.gov/downloads/Drugs/%20GuidanceComplianceRegulatoryInformation/Guidances/UCM338287>.

her ability to act on it, as if one presses down on the gas pedal but there is no response.

As these vignettes show, even someone still able to live independently can lose the abilities required to understand her situation, to make a decision and to follow it through.

It is useful to think about the factors required for successful completion of VSED, in juxtaposition to characteristics of early stage LOAD. One of the great strengths of the Hastening Death by VSED: Clinical, Legal, Ethical, Religious, and Family Perspectives conference¹⁷ was the descriptions of the VSED process from family members and physicians who had supported people who had chosen to die in this fashion. Putting “flesh on the bone” in this way enabled ethicists and legal scholars to think more productively about the issues raised by VSED.

Two conference themes highlighted the difficulties of using VSED in the context of dementia. One conference theme was that the successful pursuit of VSED required people who had exceptional focus and strength of will. Palliative care physician Timothy Quill noted that VSED “requires tremendous discipline” and “strong-willed, competent,” goal-oriented people.¹⁸ Reinforcing that picture, Judith Schwarz writes:

The ingredients necessary for success . . . [include] . . . a fully informed, decisionally [sic] capable patient who had a determined will to hasten her death, access to hospice or palliative medical oversight, and supportive care-givers who could provide round the clock care when it became necessary.¹⁹

¹⁷ Margartet Battin et al., Presenters, Address at the Seattle University School of Law Symposium, *Hastening Death by VSED: Clinical, Legal, Ethical, Religious, and Family Perspectives* (Oct. 14-15, 2016).

¹⁸ Timothy Quill, Address at the Seattle University School of Law Symposium, *Hastening Death by VSED: Clinical, Legal, Ethical, Religious, and Family Perspectives* (Oct. 14-15, 2016).

¹⁹ Judith Schwarz, *Sarah’s Second Attempt to Stop Eating and Drinking: Success at Last*, 6 NARRATIVE INQUIRY BIOETHICS 99, 100 (2016).

Bioethicist Paul Menzel agrees that “unless eating and drinking have become a physical burden, VSED involves unmistakable will. And following through on it requires that people be resolute in their view that the expedited death they seek is indeed what they want.”²⁰

A second conference theme highlighted the necessity of substantial logistical support from family and from skilled palliative care professionals. At various points in the process, many persons pursuing VSED experience severe discomfort, anxiety, or delirium, which needed to be treated with medications.²¹ Successful VSED also requires caregivers willing to remind the person of *why* they are refusing food and water. As one caregiver noted, reminding the person of their end goal can ensure success:

On the fourth and fifth days of Alan’s fast, he asked me for water. Both times, I reminded him that he wasn’t eating and drinking so he could avoid living into the late stages of Alzheimer’s disease. Then I said, “Would you like me to give you a glass of water, or can I spray your mouth with mists of water until you are relieved?” Both times, he replied, “Just use the mists of water.”²²

Thus, it appears very unlikely that a person in the early stages of dementia, while still able to form and express an opinion, would be able to succeed in VSED. The lack of self-awareness and loss of executive function so common to early-stage LOAD is a bad fit since determination and focus are necessary for successful VSED.

B. Middle Stage LOAD

It might seem like a good strategy to enjoy the relatively high quality of life that characterizes the mild stage of LOAD, and then plan to use VSED as one enters the long middle stage. However, the obvious problem is that by the middle stage, one can no longer be said to be competent to make life-and-death decisions; one would have to rely on an advance directive

²⁰ Paul T. Menzel, *Merits, Demands, and Challenges of VSED*, 6 NARRATIVE INQUIRY BIOETHICS 121, 121 (2016).

²¹ Linda Ganzini, *supra* note 3.

²² Phyllis Shacter, *Not Here by Choice: My Husband’s Choice About How and When to Die*, 6 NARRATIVE INQUIRY BIOETHICS 94, 96 (2016).

instructing others to withhold food and water. For very good reasons, such reliance would be quite risky. The persons you trusted to follow your advance directive might fail to follow through for a number of reasons. They might crumple before societal or familial pressures, or begin to question whether they could live with following a course of action they would not want for themselves. This situation leads to what Stanley Terman has called, “Dementia Fear: If I wait too long, I will no longer be able to die when I want.”²³ In other words, “I want to live as long as I have capacity, but if I wait until I have lost capacity, I will no longer be able to take control of what happens to me.”²⁴ People may end their lives before they really want to, for fear that by living too long they will miss the window of opportunity for autonomous action.

Terman claims that he has an “Ironclad Strategy” to counter this problem so that no one need end her life earlier than she wishes. The strategy basically involves a number of modalities (e.g., videos) that make it crystal clear to one’s family and others, exactly what one wants should one become mentally incapacitated.²⁵ However, I find this strategy quite unconvincing. A person in the middle stage of AD still experiences thirst and hunger, is interested in food, and can express that interest. No matter how clear the directive, can one really imagine refusing that person food and drink if the person asks for a cookie or complains about hunger? That worked for Alan Shacter because he was only in the early stage of AD and could recall his reasons for refusing food and water (and had an unusually brave and determined spouse);²⁶ that would not be true of most persons in the middle stage.

²³ Stanley A. Terman, *To Live Long Enough to Warm the Hearts of Others: Reflections on Informing my Patient about a Peaceful Way to Die*, 6 NARRATIVE INQUIRY BIOETHICS 102, 102 (2016).

²⁴ *See id.*

²⁵ *Id.*

²⁶ Shacter, *supra* note 22.

Not providing such basic care as food and water to dementia patients also places an unfair burden of moral distress on their paid caregivers. Imagine the nurse or doctor who meets for the first time a pleasant, cheerful, demented person and is then told not to give that person food or water because of the advance directive of the prior, competent person whom she has never met.

In fact, advance directives can only be relied on (if ever) when the person has reached the final, severe stage of LOAD. As we see below, for most people, that stage is far too late.

C. Late Stage AD

Menzel and co-author Colette Chandler-Cramer²⁷ argue for VSED when the person, who had created an advance directive while still competent, has entered the final, most severe stage of dementia. This seems like a plan with a high likelihood of success, if one's goal is to avoid the final stage of LOAD. However, that does not appear to reflect the goals of most people who are contemplating taking control over the timing of their death. Most people express concern that AD will burden their families or exhaust resources that they would rather use for family members or charitable goals.²⁸ As one person memorably wrote in his advance directive, "Just because I may suffer from a disease that robs me of my cognitive capacity, that doesn't mean that I've made a decision that the prime beneficiaries of my estate shall then become hospitals, nursing homes, doctors, or leasers of medical devices."²⁹

²⁷ See Paul T. Menzel & M. Colette Chandler-Cramer, *Advance Directives, Dementia, and Withholding Food and Water by Mouth*, 44 HASTINGS CTR. REP. 23 (2014).

²⁸ See Dena S. Davis, *Alzheimer Disease and Pre-emptive Suicide*, 40 J. MED. ETHICS 543 (2014).

²⁹ Stephen R. Latham, *Living Wills and Alzheimer's Disease*, 23 QUINNIPIAC PROB. L.J. 425, 426-27 (2010).

It is notable that women are afflicted with Alzheimer's more often than men (even controlling for women's longer lifespan),³⁰ and that it is women who are most likely to provide the "informal," unpaid labor to care for family members with dementia, often sacrificing their own careers or relationships in the process.³¹ Thus, women with a feminist perspective might be especially concerned not to burden daughters, nieces, and daughters-in-law.

Another common concern is that ending one's life with dementia will distort the narrative of our lives. Ronald Dworkin writes, "We worry about the effect of [our] life's last stage on the character of [our] life as a whole, as we might worry about the effect of a play's last scene or a poem's last stanza on the entire creative work."³² When that final scene lasts an average of eight years, one can reasonably fear that it will obscure the path of one's life. As legal scholar Norman Cantor declared, ending life with dementia would be "a stain on my memory."³³

As Menzel and Chandler-Cramer describe appropriate circumstances for VSED, the person requires "artful encouragement to swallow," spoon feeding, and nutritional smoothies; the person either actively resists being fed, or appears indifferent. Someone who expresses pleasure at being fed (perhaps by smacking her lips) or distress or puzzlement about lack of feeding is not a candidate, despite the wording of her advance directive.³⁴ By the time one has reached this stage, it seems that the goals and concerns

³⁰ 2014 *Alzheimer's Disease Facts and Figures*, ALZHEIMER'S ASS'N, (Mar. 2014), http://www.alz.org/documents_custom/2014_facts_figures_fact_sheet.pdf.

³¹ *Id.*

³² ROBERT DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 199 (Alan A. Knopf ed., Vintage Books, 1st ed. 1994).

³³ Norman Cantor, Address at the Seattle University School of Law Symposium, *Hastening Death by VSED: Clinical, Legal, Ethical, Religious, and Family Perspectives* (Oct. 14-15, 2016).

³⁴ Menzel & Chandler-Cramer, *supra* note 27, at 25.

described above have largely been defeated, through nearly eight years of increasing dementia.

III. CONCLUSION

Thus, it appears that, for different reasons, VSED is not a satisfactory option at any stage along the LOAD continuum. As I have argued elsewhere, if one truly wants to avoid AD, the only relatively sure option is to end one's life before one enters even the early stage. One could choose an arbitrary age, and hope that one has neither left it too late, nor sacrificed too many good years. Or, one could attempt to use the increasing panoply of biomarkers and other strategies, to identify if and when one has entered the preclinical phase of the disease, and act then.³⁵ However, I cannot believe that VSED would be the best choice to end one's life at that point, when one has no symptoms. One could certainly not count on the support of hospice staff, as one would be nowhere near the terminal stage of the disease, and the "resolute will" and self-discipline to carry it through would be beyond the range of most people (I am quite sure it would be beyond the range of this writer!).

Therefore, for all these reasons, VSED appears to be an unsatisfactory process for hastening one's death, at every stage of LOAD. Although VSED may well be an important strategy for other, non-dementing diseases, it is a frail reed indeed where dementia is concerned.

³⁵ Davis, *supra* note 28, at 547.